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I becomes we, but where is me? The unity-division paradox when caring for a relative with dementia: a qualitative study

Abstract

Background: The number of older people living with dementia is increasing. Admiral Nurses work with these individuals and their families in the United Kingdom to manage challenges associated with the condition, providing guidance, advice and reassurance, alongside practical solutions.

Aim: To explore the input of Admiral Nurses as part of people's journey to becoming and being a carer for someone with dementia.

Design: A qualitative study was conducted to describe and understand how Admiral Nurses are experienced and encountered by carers as part of their narrative around supporting a relative with dementia.

Methods: Semi-structured interviews were conducted with 19 carers between November 2017-April 2018. They lasted between 45-90 minutes. Thematic analysis was used to interpret data.

Findings: An overarching concept of 'the unity-division paradox' was derived from the data. This highlights the complex interchange between the carer with a) the person with dementia, b) other individuals, c) external services. Such interactions can make carers feel part of a larger network (unity) but also as if they are on their own, fighting on behalf of the person with dementia (division). This concept was underpinned by the following themes: 1) I becomes we; 2) My private world is encroached by dementia; 3) I'm left navigating an unwieldy system; 4) Are you with or against us?; 5) Recreating boundaries to rediscover me.

Conclusion: The identity and unique characteristics and interests of those caring for a person with dementia may be lost as they encounter tensions associated with the unity-division

paradox. Admiral Nurses can help carers feel less alone in managing internal and external struggles by supporting them to do their best for a loved one with dementia.

Implications: Understanding carers' experience and supporting their work may help to increase and sustain their capacity to provide care.

Keywords: qualitative research, interviews, carers' experiences, dementia, Admiral Nurses

List of abbreviations: AN (Admiral Nurse), HCP (Healthcare Professional), C1-19 (Carer and interview number), NHS (National Health Service), UK (United Kingdom), GP (general practitioner)

SUMMARY STATEMENT OF IMPLICATIONS FOR PRACTICE

What does this research add to existing knowledge in gerontology?

Carers are challenged by becoming part of a larger network (unity) whilst feeling alone fighting on behalf of the person with dementia (division).

A loss of personhood can occur for the carer, as they grapple with difficulties faced when navigating the healthcare system and interacting with professionals at the same time as encountering a changed relationship with the person with dementia.

Admiral Nurses can provide focussed intrapersonal, interpersonal and systemic support and do so often at the point of crisis or transition.

What are the implications of this new knowledge for nursing care with older people?

Understanding the challenges of caring for someone with dementia may help to facilitate compassionate care.

Family centred care that engages with the carer and their experience of everyday life may mitigate feelings of being alone in a world encroached by others, fighting the system to access help.

An awareness of carers loss of personhood may help to focus support on their ability to self-care.

How could the findings be used to influence policy or practice or research or education?

Policy that values the health and wellbeing of carers is essential as they are a hidden lay workforce, providing essential health and social support in the community.

Those commissioning services should consider the development of support (like Admiral Nurses) for people with dementia and their families from the moment of diagnosis, so they learn requisite skills and techniques to manage subsequent challenges.

Research to develop effective strategies that support carers and their ability to care, and subsequent inclusion of these into health education, is required.

Implications for practice

Admiral Nurses provide a range of activities that enable a carer to cope with the physical, social, emotional and organisational impact of a crisis or transition.

Preserving the personhood of a carer is essential to enable them to continue in their quest to keep a loved one with dementia as safe and comfortable as possible.

Individuals and organisations can appear to work against carers in their efforts to provide the best care possible for a person living with dementia.

1. INTRODUCTION

The World Health Organisation (2019) suggests 50 million people worldwide have dementia.

In the UK, it is estimated that 850,000 people live with the condition, which costs the economy £26 billion annually (Alzheimer's Research UK, 2019), in terms of health and social care expenditure. Costs are also borne by relatives and friends, resulting in governmental initiatives, such as the Challenge on Dementia 2020; it expresses an ambition to be the nation providing best support for these carers (Department of Health, 2015), by making them aware of support available to help them cope.

Positive aspects of caring for a person with dementia have been reported, which include feeling appreciated, developing patience, self-awareness and learning new skills (Lloyd, Patterson, & Muers, 2016; Tretteteig, Vatne, & Rokstad, 2017; Yu, Cheng, & Wang, 2018). Experiencing these positive aspects is associated with lower levels of depression and anxiety, and feeling less adversely affected by the condition (Mausbach et al., 2006; Pinquart & Sorensen, 2004). However, looking after a person with dementia can impact negatively on physical and mental well-being, one's career, finances, social life and health (Bunn et al., 2012; Cameron et al., 2011; Cooper, Balamurali, & Livingston, 2007; Feast et al., 2016). Some carers struggle to respond effectively to behavioural or psychological symptoms exhibited by the person with dementia (Feast et al., 2016). These often escalate as the condition progresses; individuals can become aggressive or wander, may have problems with eating or swallowing, encounter hallucinations or experience difficulties with continence.

In 1994, Dementia UK was established by the family of a man with dementia who was known as 'Admiral Joe' because he loved sailing (Dementia UK, 2017). This charity provides and trains Admiral Nurses (ANs) to support those affected by the condition. There are over 200 ANs working currently in the UK; the aim is to have 260 in post by the end of

2019 (Dementia UK, 2018). Although these dementia specialists can be based in care homes or hospitals, they tend to work with families at home, providing guidance on things like communication and conflict management, practical advice on challenges with sleeping and eating, and emotional support. They can act as an advocate and co-ordinate care. ANs are funded locally by a host organisation, which may be the National Health Service (NHS), a charity or local government.

Previous research has suggested that carers of someone with dementia welcome approaches to support that focus on their role in managing the condition (Sommerlad et al., 2014). ANs are available to help people in this respect. There has been research on the role of ANs in end-of-life care (Harrison Denning et al., 2012) and on the relationship between spouse, patient and AN (Quinn et al., 2012). However, there is a gap in understanding how ANs are experienced and encountered by carers as part of a more extensive narrative around supporting a loved one with dementia. The qualitative study described below set out to explore the input of these professionals as part of people's broader journey to becoming and being a carer for someone with dementia. It offers an insight into support provided by ANs, how that fits within a bigger network of help, and the facilitators/barriers to receiving appropriate outside assistance.

2. METHOD

2.1 Design

A qualitative design was adopted to understand carers' experiences. This allowed for an in-depth insight into views about what supported or constrained individuals in their caring role. It aimed to be exploratory and descriptive in nature (Polit & Beck, 2012). Approval for the

study was provided by the NHS Health Research Authority and NHS Research Ethics Committee (17/NW/0592). Steps taken to address rigour within the study are listed in table 1.

Insert table 1. Reflexivity and rigour within the study

2.2 Sample

Purposive sampling was used to recruit adults (≥ 18 years) who were or had been supported by an AN working in one area of England. ANs (who were not part of the research team) approached carers to see if they were interested in taking part, providing those who were with a study information sheet. Those interested in participating had as long as they needed to digest this information, contacting the researchers if they wished to take part either directly, or through their AN. Variation within the sample was sought, in terms of gender, relationship with the person with dementia, and length of time being a carer; reading relevant literature and discussions with ANs suggested these may play a role in how the caring role was experienced by relatives. As the study progressed, we asked ANs to identify people with specific characteristics that were lacking in the sample. For example, those who had been caring for more than a couple of months, people whose relative had moved into residential care. Participants had to speak English and be able to provide informed consent. Recruitment stopped when new information was not emerging from the interviews. Three people could not be contacted to arrange an interview, despite three attempts.

2.3 Data collection

Semi-structured interviews were conducted with carers between November 2017 - April 2018. Most were face-to-face, in a participant's home or workplace, although 3 carers opted to be interviewed by telephone. Interviews took the form of a guided conversation. Open-ended questions were used to elicit detailed responses, with a focus on the individual's experiences and perspective. A topic guide included questions to encourage participants to

discuss their experiences (see table 2) and was modified as the study progressed. For example, a question about how carers perceived changes in their relationship with the person with dementia was added.

Insert table 2: An example of questions asked during interviews

All interviews were digitally recorded, with participants' written or verbally recorded consent, which was **taken on the day**. They were then transcribed verbatim. They lasted between 45-90 minutes. Prior to being interviewed, participants completed a brief demographic questionnaire. Afterwards, the interviewer made notes about how the process proceeded, key issues raised and areas for follow-up with future participants. Data collection and analysis were carried out in tandem.

2.4 Analysis

Thematic analysis was used to manage and interpret data. This entailed looking for patterns within and across cases and taking an inductive approach, so that final themes were grounded in the words of interviewees. The stages for thematic analysis presented by Braun and Clarke (2006) were followed. Table 3 shows how the authors moved from initial codes to final themes. All members of the research team read interview transcripts, which the first author coded by hand in a Word document. This was shared with and considered by the remaining authors. Codes were clustered into similar topics (categories). These were discussed as a team, resulting in the themes described below.

Insert table 3: Summarising how analysis moved from codes to the final overarching theme

3. RESULTS

3.1 Participants

Table 4 provides an overview of the 19 carers (C) involved in the research. Several interviewees had weekly contact with their AN, as they struggled emotionally or with an aspect of their loved one's behaviour. Others had less frequent contact as they entered a period when the person with dementia was relatively stable.

Insert table 4: Overview of the participants

3.2 Overarching concept: The unity-division paradox

Caring could lead to both isolation (doing this on my own) and connectivity (becoming associated, to varying degrees, with others). This understanding informed our overarching concept: The unity-division paradox (see figure 1).

Insert figure 1: The unity-division paradox

Carers described in detail the impact of others (the person with dementia, professionals, relatives, friends) on their encounters as a carer. This 'togetherness' could be reluctantly succumbed to (e.g. having external carers coming into the home) or was depicted as an active choice they embraced (e.g. drawing on an AN for support). Hence, the overarching concept of the unity-division paradox reflects that being a carer could make individuals feel detached but, at the same time, part of a larger unit than simply 'me', whether they wished for this or not. The change in relationship with the person with dementia was stark; it prompted a sense of being needed and feeling abandoned by this person. Health and social care systems could reinforce carers' perceptions of isolation if experienced as disjointed and inhumane. ANs supported participants through this paradox to achieve equilibrium, which enabled them to continue in their caring role. When able to keep their loved one safe, content and as independent as possible, carers talked about experiencing the role as joyful and rewarding. Conversely, carers risked "losing my mind" (C10) and could become physically ill when

outside forces and their own internal turmoil resulted in a greater sense of division than unity. The following themes contributed to our understanding of the unity-division paradox.

3.3 Theme 1: I becomes we

This theme relates to the carer-person with dementia dyad and the unity-division paradox that occurred at this micro-level. Interviewees stated that the person with dementia became increasingly reliant on them, even for small things like knowing how to get into a car or use cutlery. At the same time, distance could transpire due to violent, out-of-character outbursts, which some interviewees kept hidden, not wanting others to think badly of their partner/parent. Distance also occurred when the person with dementia was unable to talk, although signs of affection were still possible (e.g. rubbing noses, smiles).

Spouses assumed more and more duties in and outside the house, resulting in an unequal partnership; C3 (wife) noted ‘it’s become more parent/child type thing... needing to organise everything you know’. Adult children talked about their unease at taking charge of a parent’s finances or coaxing them to do things (e.g. go to a day centre), which they described as a role reversal:

C10 (son): ‘It’s hard to say, trying to discipline him, like him tipping his urine away. You try and have a logical conversation, you can’t do that...that’s not right. And he just looks at you like...you can’t tell me what to do.’

Participants had to accept they may be giving and not getting much back from the person with dementia (e.g. making food that was not eaten). They also had to take on intimate care, whereby bodily boundaries were crossed:

C8 (husband): ‘... to care for my wife I’m having to have access to all her body, and she’s frightened understandably...the shock when there’s a man washing her, and undressing her, and dressing her...’

It was striking how far the emotional world of interviewees was shaped by responses and behaviours of the person with dementia; interviewees said they were happy when their loved one seemed content, or anxious when this individual showed distress. Participants tried to contain their negative emotions to avoid upsetting the person with dementia (e.g. leaving the room to silently vent or crying in the shower). This could include hiding their frustration when the person with dementia kept asking the same thing. Carers saw this as a sign of the dementia progressing, which although regarded as inevitable, was a source of dismay.

As the dementia progressed, attending to the safety and comfort of their loved one became all-consuming. In general, interviewees were stoic and reported being driven by a sense of duty (as a spouse) or giving back (as an offspring); a strong faith also helped some. Yet accepting a caring role was not always undertaken with relish:

C18 (son): ‘Some people get a lot out of caring, but I don’t really and to be perfectly honest I resent it ...’

3.4 Theme 2: My private world is encroached by dementia

This theme relates to changes in the carer’s personal environment to meet the increasing demands of dementia, which could happen even when not living with the person who had this

condition. For example, C6 (daughter) invested in technology to observe her mother remotely; this prevented her from relaxing at home as she checked constantly that nothing was amiss.

Interviewees living with the person with dementia talked about making significant adaptations to their home to accommodate the condition; removing mirrors, putting beds downstairs, installing stairlifts. Part of this change in their personal environment was to make the person with dementia as content, safe and independent as possible. C15 described steps he took to stop his wife wandering around the house at night; once she was found by the police outside alone and on another occasion fell down the stairs. This interviewee's solution was as follows:

C15 (husband): '...I locked all...the windows. And I had to block the stairway up with a chest of drawers...I started to drag that chest of drawers every night, over the opening, over the stairs. And then I used to have to put a clothes airer on top of them to stop her, so she wouldn't climb over them.'

Participants lamented losing their ability to function autonomously from the person with dementia, which meant they became more confined to their home. Whilst their social world shrank, letting others in (i.e. paid carers) became necessary. Paid carers helped with things like getting the person with dementia ready in the morning and preparing them for bed in the evening. Their presence could add to this sense of the private world being encroached by dementia, as paid carers often gave an unspecific timeframe for their arrival and were not always reliable. Several participants questioned the suitability of paid carers entering their home, some of whom were described as too task-focused; this was attributed to the limited

time paid carers had to spend with each client. Doubts were expressed about whether they had received adequate training (e.g. in communicating with someone who has dementia). However, C10 did observe that some paid carers were more adept at negotiating bodily boundaries related to incontinence:

C10 (son): ‘...I’m not comfortable with...wiping his bum and cleaning up after him. I did it when he was starting to have accidents, but it was such a stress on me ...they come in and they’d have him clean within five minutes. With me it was taking half an hour ...’

Finding opportunities for the person with dementia to spend time outside the home was seen as essential, enabling carers to attend to activities important to them, including household chores. Yet extended periods in hospital or respite care disrupted the routine of the person with dementia. This was then difficult to reinstate:

C8 (husband): ‘Ten weeks away from familiar routines...it’s been a battle to try and get her back...to where she was. So the battle...with respite is if I have too long a period, no matter how restful the respite is, I’ve got to pick up the pieces...’

3.5 Theme 3: I’m left navigating an unwieldy system

This theme highlights the struggles participants encountered when trying to access services. Being assertive and speaking out was an alien way of behaving for some. Yet they felt they had to be the vocal member of the carer-person with dementia dyad in the face of hostile and

complex systems, which C11 described as lacking ‘joined-upness...the individual bits of the system work...they just don’t work together.’ Complexity increased when the person with dementia had another long-term condition (e.g. cancer, arthritis). Uncertainty was expressed about how far other services were aware of the dementia diagnosis and whether it was a carer’s role to alert them, especially when cognitive impairment was perceived to be mild.

Working out finances for services was another problem, causing anxiety for carers about escalating costs. Some talked about a loss of privacy, as their income came under scrutiny because they were seeking financial support to which they were entitled. This could mean completing lengthy documentation:

C19 (wife): ‘...an attendance allowance...that form to fill in is an absolute nightmare...in the end I went to Citizens Advice...she [volunteer] was so sweet and she broke off halfway through [completing the form] and she made us a cup of coffee...because you do discuss problems and fears...’

Participants sometimes felt abandoned by services. This occurred at different times during the dementia journey. It started at diagnosis, when people recalled being left alone to cope with the news; this seemed to be particularly so if medication was not accepted:

C11 (daughter): ‘And I said, you know, so we’ll be in contact with you again. Oh no, only if you decide to take the medication we stay in contact with you.’

Several interviewees reported a lack of clarity, **prior to meeting an AN**, about where to turn when escalations in the condition transpired. Experiences of hospitalisations, in particular, were not necessarily pleasant, with some carers being made to feel that their loved one was a burden on society:

C14 (daughter): ‘...I asked on several occasions, asked the consultant, could she be transferred to the ward where they knew her... he...said well this isn’t a nursing home, this is an acute hospital, your mum shouldn’t be here... it’s as if the medical profession...has very happily taken on this attitude towards patients who are in the same situation as mum and are termed bed-blockers.’

3.6 Theme 4: Are you with or against us?

This theme follows on from the system-wide perspective presented previously. It centres on encounters with individuals during the caring journey, who could be perceived as allies or adversaries. Interactions with healthcare professionals (HCPs) varied. In certain instances, general practitioners (GPs) were said to support carers emotionally as well as practically. Others depicted these HCPs as seemingly unconcerned or offering unconstructive advice:

C1 (husband): ‘I’m having trouble with constipation, I’m having trouble draining my bladder. And all he [GP] said is take a holiday.’

Views of other professionals (e.g. nurses, consultants, social workers) also diverged.

Helpful interactions were with HCPs who were accessible, empathetic and followed up on

what they said they would do, in contrast to those treating carers as a case, not an individual, and failing to listen to their specific story.

Carers could face resistance from the person with dementia, who might underplay their difficulties to HCPs and refuse to let friends and relatives know about their diagnosis. This further limited the support a carer could draw upon:

C6 (daughter): ‘...if people like social services go round, mum puts on this yes, oh I do this, I go on the Ring and Ride, I shower, I do this, I do the garden. When reality, she does nothing of that.’

Some interviewees were concerned about reaching out to friends and family, stating that people had their own lives to lead and responsibilities (e.g. children, jobs); **this was something ANs encouraged them to do**. Partners could be a significant source of support; a sympathetic ear who provided practical assistance (e.g. taking them to see their parent, having the person with dementia stay in their home). Interaction with siblings could be difficult if a brother or sister lived abroad or found it hard to accept a change in their parent and, consequently, stayed away. Some interviewees had children they could call on when necessary (e.g. to sit with the person with dementia or attend medical appointments). Having friends who had undertaken a similar caring role could be useful, because they understood the situation. Conversely, other members of carers’ social world were depicted as not appreciating what such work entailed:

C7 (son): ‘...my brothers definitely, they don’t know half of it you know. They’re very much, see mum for two hours a week and if it’s all hunky dory, they go off.’

3.7 Theme 5: Recreating boundaries to rediscover me

This theme relates to processes undertaken by ANs to help carers. **Table 5 outlines the key activities that interviewees described in relation to these nurses.**

Insert table 5: Activities undertaken by ANs as described by interviewees

ANs were singled out by interviewees as bridging divisions between different members of their social world, including those only present due to the dementia (e.g. HCPs). They were described as helping interviewees deal with the fractured nature of services, arranging and co-ordinating appointments, and supporting them in making decisions about escalating care (e.g. bringing in paid carers, accessing respite and residential care):

C16 (daughter): ‘...they never say do this, do that...they just know exactly what questions to ask. And they were going so, is your dad getting up the stairs...because if mum was here she’d be wanting the loo ten times a day...they gave me a bit of strength to make the decision [to transfer her mother to residential care].’

A couple of participants (C4 and C13) benefitted from attending a course on dementia because it enabled them to appreciate what was happening to their loved one. This was seen as preferable to written information, which several interviewees mentioned as providing them with a basic understanding but not specific enough to their situation. In contrast, ANs’ experience and knowledge of dementia were welcomed; it enabled them to suggest solutions

to particular difficulties and with managing crises. They were also credited with addressing emotional aspects of caring, reassuring interviewees they were doing a good job and that feelings they experienced (e.g. anger, frustration) were natural and understandable. They helped carers deal with the guilt that could arise in this role (e.g. when the person with dementia did not eat, when deciding to transfer the person with dementia to residential care). ANs encouraged carers to take time to themselves and helped them process the loss that occurred following a changed relationship with the person with dementia. Having someone they thought understood prompted carers to open up about how they really felt:

C1 (husband): ‘...a breath of fresh air...she’s [AN] been tremendous. Just the fact that we can talk easily about anything... comes and talks, spends an hour or so, an hour and half here.’

ANs were described as bringing order to the carer’s world. They helped interviewees make sense of the confusion experienced when embarking on caring. However, encounters with an AN might occur only after the carer had endured significant distress:

C13 (wife and daughter): ‘...if I’d had an Admiral Nurse at [Husband]’s initial diagnosis...I don’t think I would have struggled for so many years and wouldn’t have had the resentment. I wouldn’t have had the fear, because you don’t know what’s going to happen.’

Concern was expressed by interviewees about how long the AN would be available to them. This caused anxiety because, overall, ANs were painted as vital in participants' ability to continue looking after their loved one, giving them permission to think of themselves as separate from the person with dementia. ANs encouraged interviewees to prioritise activities they enjoyed so their identity was not limited to being a carer, be that attending to an allotment, volunteering, meeting with friends, or exercising:

C18 (son): 'She [AN] said I've got to be more strict...we're working on that and she's [mother] is going out one day a week [to a day centre]...the Admiral Nurse has explained to her [mother] that she needs to do this because I need a break...I'd love to go out for the day on my bike.'

4. DISCUSSION

This study resulted in the development of a novel way of conceptualising experiences of those caring for a person with dementia, through the overarching concept of the unity-division paradox. Carers became closer to the person with dementia emotionally and physically, as they took a leading role in the relationship. At the same time, dementia could fracture their bond as the relationship changed, and as the carer became frustrated and exhausted. A sense of being alone was exacerbated when services were encountered as uncoordinated and unhelpful, yet external support was required as the condition progressed.

Kitwood (1997) wrote about person-centred dementia care, **and much has been said about recognising and respecting the agency of someone with this condition, who is still "in the world, a sentient, relational and historical being" (Kitwood, 1993 p. 541). This has resulted in discussion around 'personhood' within dementia, which according to Kitwood (1997 p.8)**

refers to “a position or social relationship that is bestowed on one human being by ‘others’, in the context of relationship and social being.” The notion of ‘personhood’ has been used in relation to people with dementia to refer to their unique humanity; attributes they embody that make them a person, which may be eroded as they come to assume, in the minds of others, a restricted position within society (Dewing, 2008). Our research highlights that this **minimised status and loss of personhood** may extend to carers, as they struggle to navigate the unity-division paradox. Carers’ personhood seemed to diminish as dementia encroached all aspects of their social and home life, their emotional and physical well-being, and their relationships with others.

Loss of personhood can transpire when someone’s identity as a carer comes to dominate, yet positive aspects of caring are possible, such as being satisfied they have provided safety and comfort, experiencing moments of fun and affection, and feeling personal accomplishment and growth (Lloyd et al., 2016; Yu et al., 2018). Appreciating such positive aspects can entail reappraising one’s relationship with the person with dementia and accepting change; this may include embracing outside support and even a degree of physical separation if someone moves into residential care (Tretteteig et al., 2017). As noted by Lloyd et al. (2016) positive aspects of caring do not just appear; they are developed through strategies and choices made by a carer. However, positive aspects of caring may be missed when struggling to navigate services; ANs can assist carers to see beyond these challenges.

Previous research has reported that those seeing an AN are highly satisfied (Maio, Botsford, & Iliffe, 2016); they like having someone who tailors support to their current needs (Bunn et al., 2016). Our research looked in more detail at what prompts that satisfaction in light of the overall caring journey. It showed that ANs negated carers’ experience of the unity-division paradox, enabling them to integrate this new role with their previous sense of identity and history with the person with dementia. Interviewees valued having someone they felt was on

their side in the form of an AN, who helped them to not just navigate a system but to fight it when required. This left space for carers to find meaning in caring and to feel positive about making a loved one safe and comfortable (Shim et al., 2013).

ANs appeared to protect the personhood of the carer at three levels (see table 6). However, contact with ANs was serendipitous; carers were often only referred to an AN (e.g. by a GP) when reaching a low ebb. This underlines the importance of appropriate support at all stages of the caring journey, starting at diagnosis, when carers need time to ask questions and process information (Dean et al., 2014), through to managing an escalation in care and during crises, such as hospitalisations (Jurgens et al., 2012).

Insert table 6: How ANs support carers' personhood

4.1 Implications for practice

We have several proposals for helping carers navigate the unity-division paradox and to maintain their personhood. A lack of continuity of care means that a key worker, like an AN, is essential for carers (Stephan et al., 2018), from the point of diagnosis, to establish an action plan and enable individuals to prepare for what might arise. This would include providing information about dementia upfront, with time available to address carers' questions.

Uncertainty about the future was present in transcripts because the course of dementia was unclear; a lack of guidance from HCPs increased carers' emotional turmoil. Bringing the unsaid into the open seems important, including negative feelings like guilt and anger, challenging behaviours of the person with dementia (violence, incontinence) and a loss of intimacy. Having avenues for discussing these issues may help to reduce any shame and secrecy. Other authors have talked about using decision aids to facilitate difficult conversations, particularly in relation to escalating care provision (Lord et al., 2016).

Likewise, access to a person for advice on finances and application for attendance allowance may be useful.

During the analysis, a poem was written by one of the authors (ET) to convey an essence of the key findings (see table 7). It may have some utility for developments in practice and make the findings easily accessible to a diverse audience.

Insert table 7: Carer's poem

4.2 Future research

The unity-division paradox may extend to other caring experiences but seems particularly relevant to dementia given the vulnerability of those with this condition, which means the carer-person with dementia dyad becomes asymmetric (Tretteteig et al., 2017). Further research could explore how it relates to other situations (e.g. when people are physically compromised but mentally alert, or to those caring for a child with a long-term condition).

Our research did not consider how people caring for someone with dementia and a learning disability experienced this role; hence, further research could investigate this topic. Although the unity-division paradox held for both spouse and offspring carers, interventions could be developed and tailored to the differing relationship someone holds with a person with dementia.

4.3 Limitations

It was reassuring to note that our findings reflect those reported in a large European study (Stephan et al., 2018). We shared the findings with 5 people who had a relative with dementia (not interviewees). They all felt the themes reflected their own experiences. However, one did state that although our findings touched on issues that were key when she cared for a parent, she felt that the changeable nature of dementia behaviours, the disruptive influence on family dynamics, and stigmatisation within society were more profound in her personal situation.

Even though 60-70% of those caring for a person with dementia are female (Alzheimer's Research UK, 2015), we had slightly more males taking part. This may be a reflection of those coming forward or could indicate that ANs are being accessed or mentioned more often to males, whilst females are left to cope alone (Alzheimer's Research UK, 2015). Participants were recruited via ANs, so more negative views of this service may not have been accessed. We did ask ANs to identify non-Caucasian carers but none came forward to be interviewed.

5. CONCLUSION

The unity-division paradox is a novel concept that highlights tensions carers face due to shifting constellations of individuals and services involved in helping them reach their aim of keeping the person with dementia safe, content and as independent as possible. This conflict can arise as they seek to balance their own and the needs of others. It highlights the complexity of navigating this role due to the diverse systems that provide support, which can be experienced as hostile and uncaring. ANs played a key role in helping carers to be confident in traversing this paradox, enabling and encouraging them to retain their personhood. These nurses are only part of an unwieldy system that people enter upon undertaking a caring role, but their presence seemed essential in offering advice and comfort. They were depicted by interviewees as preventing them from feeling alone as they sought to do their best for a loved one with dementia.

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TABLES

Table 1: Reflexivity and rigour within the study

Two researchers conducted interviews (ST completed 15, ET completed 3). Neither had been recently involved in dementia care and they were not known to participants prior to interview. Both are health services researchers, who have conducted many interview studies with patients and caregivers. Throughout the project, a study journal was kept by ST to note emerging ideas in relation to data, codes, categories and themes, and to document processes associated with conducting the research. The third author, an experienced health services researcher with relatives who had dementia, commented on developing categories and themes. The research team met throughout the study to discuss the data and how sampling was progressing.

Table 2: An example of questions asked during interviews

- What is it like to look after [your husband/wife/parent] with dementia?
- What support have you received in this role (from whom/which services)?
- What is your social life like?
- How would you describe your health?

Table 3: Summarising how analysis moved from codes to the final overarching concept

| Overarching concept: The Unity-Division Paradox | | | | | |
|---|--|--|---|--|--|
| Themes | <i>I becomes we</i> | <i>My private world is encroached by dementia</i> | <i>I'm left navigating an unwieldy system</i> | <i>Are you with or against us?</i> | <i>Recreating boundaries to rediscover me</i> |
| Categories | <p><i>A changing relationship</i></p> <p>Having to think and act on behalf of the person with dementia</p> <p><i>Establishing new modes of interaction</i></p> <p>Carers learn to respond to an altered level of</p> | <p><i>Creating a benign environment</i></p> <p>Changes in the home to provide a safe and calm living space</p> <p><i>Becoming confined to home</i></p> <p>Carers' social world shrinks as they have to</p> | <p><i>Speaking out</i></p> <p>Being assertive and advocating for the person with dementia, when systems are perceived as hostile</p> <p><i>Working out finances</i></p> <p>Worrying about how to pay for services and</p> | <p><i>Interacting with professionals</i></p> <p>Experiences with professionals varied</p> <p><i>Facing resistance from the person with dementia</i></p> <p>An unwillingness by the person with</p> | <p><i>Providing advice and support</i></p> <p>The AN offers solutions and information about dementia and how to manage common problems</p> |

| | | | | | |
|--|---|---|--|--|---|
| | <p>intimacy with the person with dementia</p> <p><i>Putting me aside</i></p> <p>The all-consuming nature of caring subsumes other aspects of the carer's daily life and means remaining stoic</p> | <p>be increasingly available to the person with dementia</p> <p><i>Letting others in</i></p> <p>Paid carers' impact on the home, as both a help and a potential hindrance</p> | <p>having to complete related bureaucracy</p> <p><i>Feeling abandoned</i></p> <p>Struggling to have one's needs and concerns heard</p> | <p>dementia to accept and let others know about their situation</p> <p><i>Drawing on close others (or not)</i></p> <p>Support from family and friends was invaluable, but sadness was expressed when close others stayed away or made unhelpful comments</p> | <p><i>Acting on behalf of the carer</i></p> <p>The AN takes on an intermediary role in a range of situations</p> <p><i>Addressing emotional impacts of caring</i></p> <p>ANs are available to carers to deal with their emotions, including times of crisis</p> |
|--|---|---|--|--|---|

| | | | | | |
|--------------|--|---|--|--|--|
| Codes | <ul style="list-style-type: none"> • Thinking for them • Shifting power relations • An unequal partnership • Feeling sad or anxious by loved one's behaviour • Witnessing a decline • Putting person with dementia first • Neglecting own needs • Becoming reliant on carer • All-consuming | <ul style="list-style-type: none"> • Developing coping strategies • Having to accept help • Making changes to home • Feeling confined to home • Social life diminishing • Lacking flexibility • Being unable to switch off at home • Questioning suitability of paid carers | <ul style="list-style-type: none"> • Struggling to arrange support • Being an advocate • Having finances questioned • Paying for support • Completing forms for support • No continuity of care • Refusing to accept medication • Feeling abandoned by services • Being left to cope alone at diagnosis | <ul style="list-style-type: none"> • Varying interactions with GPs • Needing professionals to be empathic and reliable • Feeling let down by professionals • Not wanting others to know • Withdrawing of others • Experiencing negative comments from others • Turning to friends who had been carers | Role of AN: <ul style="list-style-type: none"> • Co-ordinating care • Talking things through • Providing information • Offering practical advice (e.g. medication, eating, incontinence) • Providing a sympathetic ear • Helping carer to feel emotionally stronger • Reassuring carer they are doing a good job |
|--------------|--|---|--|--|--|

| | | | | | |
|--|---|--|--|--|--|
| | <ul style="list-style-type: none"> • Containing emotions • Crossing bodily boundaries • Sense of duty • Giving back • Dealing with changed personality • Non-verbal communication • Eating concerns • Sleeping difficulties | <ul style="list-style-type: none"> • Encouraging the person with dementia to spend time outside the home • Disrupting routines | | <ul style="list-style-type: none"> • Others failing to appreciate what caring involved • Not wanting to burden others • Drawing on family for support | <ul style="list-style-type: none"> • Acting as an intermediary or advocate • Being there when needed (reliable) • Following up on things • Ensuring carer doesn't feel alone |
|--|---|--|--|--|--|

Table 4: Overview of the participants

The 19 participants (9=female) looked after 18 different people; the sample included a father and daughter who were interviewed together. Their average age was 62.29 years (range = 29-86). All were White British. Their relationship to the person with dementia was as follows: 6 husbands, 4 wives, 1 grandson (referred to as 'son' in the findings to avoid identification), 4 sons and 5 daughters (one person cared for a husband and both parents, and another two cared for their mother and father). In terms of residential status, 13 carers lived with the person with dementia. In 2 cases, the person with dementia was in residential care; for another her husband had died 5 months before the interview. Diagnosis had been made 6 weeks before the interview for one person, 12 years ago for another, but for most individuals it was within the last 2-3 years.

Table 5: Actions undertaken by ANs, as described by interviewees

- *Acting as a sounding board*
 - Giving advice on medication, incontinence, food refusal, helping with decision-making on things like residential care or accessing day centres
- *Offering a sympathetic ear*
 - Someone that carers can open up to, there to listen to them in a non-judgmental way
- *Being an advocate*

- Legitimising and facilitating carers' requests for external help, following up on their requirements from outside services, moving things forward when needed
- *Providing comfort*
 - Reassuring carers they are doing a good job, helping them feel emotionally stronger
- *Taking on the role of ally*
 - Someone reliable, who is there for carers so they do not feel alone and gives them permission to address their own needs

Table 6: How ANs support carers' personhood

- *Intrapersonal:* Those caring for a person with dementia encounter a plethora of emotions, including frustration, uncertainty and guilt (Prorok, Horgan, & Seitz, 2013). ANs help carers deal with intrapersonal issues by:
 - Offering external validation for their caring endeavours and reassurance that they are doing a good job
 - Inspiring hope that they can cope and that their situation can improve
 - Providing non-judgmental emotional support, giving them permission to accept difficult feelings and to attend to their own needs
 - Helping them make decisions about accessing external services, including residential care

- *Interpersonal:* Role transitions follow a diagnosis of dementia (Prorok et al., 2013). Friends and family have been defined as crucial but may not be accessed due to concerns about discussing the diagnosis with others (Dean et al., 2014). Interactions with HCPs have also been described as varying (Stephan et al., 2018). ANs help carers deal with interpersonal issues by:
 - Normalising behaviours of the person with dementia and providing practical advice on toileting, medication and eating
 - Persuading carers to draw on formal and informal sources of support
 - Talking to family members to encourage them to assist the carer
 - Giving carers confidence to be assertive during interactions with HCPs
- *Systemic:* Accessing services can be perilous, with support provided not necessarily optimum, easily accessible or co-ordinated (Prorok et al., 2013). ANs help carers deal with systemic issues by:
 - Acting as an intermediary, co-ordinating services when necessary
 - Sharing their knowledge of how systems work

Table 7: Carer's poem

Carer's poem

He was my true love, I loved him so
And it does hurt to watch him go.
I still love him but it is not the same
He has no clue it is a different game
I work so hard all day and night
Our future gone, I do not take flight.
I have changed our world so he can thrive
But it saddens me so little is left alive.
The bit that is me has long since gone
I strive to find it but it seems so wrong.
I can't bear to see him lost and scared
If we stay together a bit of me is spared.

I weep on my own when he is fast asleep
I cannot speak the pain it runs so deep.
It is horrible to see anger and fear in his eyes
Then he carries on as normal whilst my heart cries.
The system feels brutal, unsupportive all the way
Battling against an unknown foe, mostly you just pay.
Being alone is how I feel although family provide some light
The future it winds slowly and mostly flickers out of sight.
Staff that listen, share the burden are sometimes found
Sustaining us on our journey their impact so profound.

Figure 1: A summary of the unity-division paradox